Where People Die. A Critical Review

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ABSTRACT

There is a great discrepancy in society between the number of people that prefer to die within their home and the number of cases where this wish actually becomes reality. It is generally assumed that the most frequent place of death in Western societies is not the home but an institution, such as a hospital or nursing home. But what is the actual distribution of places of death? Contemporary discourse on the institutionalisation of dying is subjected to critical scrutiny in light of empirical data. Our review shows that places of death are not distributed at random but reflect social patterns. Socio-demographic relationships involve factors such as gender, socio-economic status, or the degree of urbanisation. Moreover, the fairly high and, over many years, constant percentage of people dying at home ranging between 20 to 30 percent additionally casts doubt on the classic institutionalisation of dying thesis.

Keywords: place of death; dying; institutionalisation; death; end-of-life research

INTRODUCTION

Due to the social significance and embeddedness of attitudes and actions that go along with the process of dying, dying not only constitutes a primarily psychological or medical but also a social reality. To the extent that scientific research has given attention to places of death, it has been concerned with issues relating to the degree of institutionalisation of dying in modern society. Historically, in Western societies, dying has occurred at home (Ariès 2005). There is general agreement that the process of dying and the people involved therein have shifted from the personal privacy of the home to the professional enclaves of hospitals and nursing homes in the past sixty years (Elias 2002). The argument suggests that dying now increasingly occurs in medical institutions, such as the hospital (see Howarth 2007: 33). The idea of a sequestration of death refers to the general assumption that the majority of people now die in institutions, away from the public gaze (see Howarth 2007: 24). Notions of hospitalisation or institutionalisation in discourses on the place of death stand for the banishment of death from everyday life (Nassehi and Weber 1989; Schmied 1985). The concept of medicalisation suggests that dying has been located within the domain of medical science (Howarth 2007). Death in the hospital is associated with a new “style of dying” (Ariès 2005: 751). The term “social isolation” is frequently used in this context. It signifies that because of the degree to which dying is institutionalised, the dying person is left to die on his or her own since the process of dying by necessity implies that the person must withdraw from social life.

In the following section, the various perspectives and assumptions about places of death outlined above will be compared with the image of dying reflected in various empirical studies on places of death. Contemporary discourse on the institutionalisation of dying is subjected to critical scrutiny. The literature review is based on the distribution of people dying in hospitals, retirement or nursing homes, hospices, or at home. In addition, other

factors determining places of death, such as medical, structural, socio-demographic, and individual factors, will be summarised.

WHERE DO PEOPLE DIE?

There is a great discrepancy in society between the number of people that prefer to die within their home and the number of cases where this wish actually becomes reality. Studies reveal that the large majority of people asked about their preferences wish to die at home and not in an institution. Studies show that this holds true for 50 to 90 percent of those asked about their preferences (Bell et al. 2010; Thorpe 1993). According to a survey conducted within the context of Switzerland's National Strategy for Palliative Care, 73 percent of the respondents stated they would prefer to die at home.[1] These values, however, are diametrically opposed to the number of people that actually die at home, the share of which generally hovers around 20 to 30 percent (e.g. Ochsmann et al. 1997; Dreßel et al. 2001; van Oorschot et al. 2004). To distinguish the *imagined* from the *real* place of death, we will provide an overview of the major European studies on the actual distribution of places of death in two synopses (Table 1 and Table 2). The place of death in the wake of cancer is illustrated separately in Table 2. We consider studies in German and English from different European countries and regions. Our aim is to give an overview of empirical trends, the actual distribution, and social regularities with regard to places of death. The literature review is predominantly based on studies that provide official data of the places of death (Ochsmann et al. 1997; Higginson et al. 1998; Davison et al. 2001; Freilinger 2009; Mikulasek 2010; Cohen et al. 2006, 2007; Houttekier et al. 2009). Cohen et al. (2006, 2007) and Houttekier et al. (2009) had privileged access to official data from death certificates, which provide detailed demographic information such as cause, time and place of death, place of residence, age, education, occupation, sex, nationality, and civil status. Thus, the data can be directly used for bivariate and multivariate analysis without having to combine diverse statistical data from different statistical sources as Ochsmann et al. (1997) were forced to do in their study in Germany.

All other studies (listed in table 1) conducted surveys and relied on information on the places of death obtained from the interviewees (patients, family members, and medical staff). Moreover, the studies by Fischer et al. (2004) and Bickel (1998) are based on an analysis of official death certificate data in combination with a survey (interviews with medical staff, n=3358 (Fischer et al. 2004), and family members, n=958 (Bickel 1998)).

The literature review must be viewed within the following limitations. We do not claim to provide a complete review of international studies on places of death. Specific studies about death in hospices, the distribution of places of death for people with dementia (e.g. Houttekier et al. 2010; Verne et al. 2011), for children with cancer (e.g. Shah et al. 2011; Higginson and Thompson 2003), or for people with HIV (e.g. Guthrie et al. 1996) are excluded from the literature review.

The distribution of places of death between hospitals, retirement or nursing homes, at one's own or another person's home varies considerably among countries and regions, as the synopsis in Table 1 shows. Apart from the common fact that hospitals are the most frequent place of death in all studies, the figures given for hospitals as the place of death may differ significantly in a cross-country comparison, for example ranging from 37.2 percent in German-speaking Switzerland (Fischer et al. 2004) and 39.8 percent in Denmark (Cohen et al. 2007) to 63 percent in Belgium (Houttekier et al. 2009). In Germany the percentage of

[1] http://www.bag.admin.ch/themen/medizin/06082/06426/index.html?lang=de.

hospital deaths ranges from 44.1 (Ochsmann et al. 1997) to 49.7 (Bickel 1998). When comparing this data with Schmied's data (1985: 42) on the proportion of people who died in hospitals in the 1960s and 1970s, we notice relative stable percentages for Germany. The share of people who died in hospitals was at 45.4 percent in 1962, 53 percent in 1972, and 54 percent in 1975. Dying in the hospital varies by region, and various trends have been observed in the past decades. In German-speaking Switzerland, for instance, dying in the hospital has declined from 56 percent in 1969 to 37.4 percent in 2001 (Fischer et al. 2004). In England and Wales, however, it has increased in the periods from 1966 to 1976 (Bowling 1983) and 1981 to 2001 (Ahmad and O´Mahony 2005). While we observe a shift in the place of death from hospitals to retirement and nursing homes, the degree of institutionalised dying remains constant (Fischer et al. 2004). In Belgium, for example, hospital deaths decreased from 55.1 to 51.7 percent and care home deaths increased from 18.3 to 22.6 percent between 2007 and 1998, whereas the percentage of home death remained stable (Houttekier et al. 2011). The incidence of death in retirement or nursing homes also varies strongly by region and country. The number of people that die in one of these facilities has increased while the ratio of increase shows some variation (see table 1). In 2001, 33.5 percent died in a retirement or nursing home in German-speaking Switzerland, which is double the rate in 1986 (Fischer et al. 2004). In Austria, the figures range from 13.4 percent in 1995 to 15.2 percent in 2010 (Freilinger 2009; Mikulasek 2010). Exceptions are the German state of Rhineland-Palatinate at 37.3 percent in 1995 (Ochsmann et al. 1997) and the German city of Jena at 33.7 percent in 2003/2004 (van Oorschot et al. 2005). In Brussels, on the other hand, the rate of those dying in their private home is particularly low at 15.1 percent (Houttekier et al. 2009).

Table 1: Distribution of places of death (data given in percent)

Author	Year	Location	Sample(s) (n)	Hospital	Retirement (RH) and/or nursing home (NH)[1]	At home (AH) and/or other private residence (PR)[2]
Bowling	1983	England, Wales	n.s.	1966: 54 1976: 60-70	n.s.	n.s.
Cartwright	1991	England, Wales	n.s.	n.s.	n.s.	1969: 42 AH 1987: 24 AH
Clifford et al.	1991	Victoria (AU)	n.s.	57	14 NH	21 PR
Ochsmann et al.	1997	Rhineland-Palatine (D)	19,672	44.1	12.8 RH	37.3 AH
Bickel	1998	Mannheim (D)	958	49.7	21.2	n.s.
Davison et al.	2001	Belfast (IR)	n.s.	1977: 50 1987: 40 1997: 42	1977:13 1987: 25 1997: 23	1977: 35 1987: n.s. 1997: 28
Fischer et al.	2004	German-speaking Switzerland	1969: 58,002 1986: 60,105 2001: 3,358	1969: 56 1986: 55 2001: 37.2	1969: n.s. 1986: 14 RH 2001: 33.5 RH/NH	1969: 38 1986: 28 AH 2001: 22.7 AH
Ahmad, O´Mahony	2005	Wales	1981: 35,015 2001: 32,966	1981: 56.7 2001: 61.7	1981: 5.7 2001: 16.2	n.s.
van Oorschot et al.	2005	Jena (D)	90	52.3	12.8	33.7
Cohen et al.	2006	Flanders/BE	55,759	53.7	19.8 NH	24.3 AH
Cohen et. al	2007	Flanders/BE DK SE CH	12,492	Flanders: 50 DK: 39.8 SE: 43.9 CH: 37.3	Flanders: 21 DK: 30.6 SE: 33.6 CH: 33.7	Flanders: 26.5 DK: 25.4 SE: 21.2 CH: 22.7
Gomes, Higginson	2008	England, Wales	n.s.	n.s.	n.s.	1974: 31 2003: 18
Freilinger	2009	Austria	ca. 40,000	50	1995: 13.4/8.4 2006: 15.5/13.5	30
Houttekier et al.	2009	Brussels (BE)	3,672	63	21.6	15.1
National End of Life Care Intelligence Network	2010	England	471,092	58	9 NH 7 RH	19
Mikulasek	2010	Austria	2002: 76,131 2010: 77,199	2002: 55.3 2010: 52.0	2002: 12.5 2010: 15.2	2002: 27.5 2010: 26.83

(Source: own illustration)

[1]: Not all of the studies reviewed make a distinction between retirement and nursing home.

[2]: Here, too, the studies fail to provide information whether the person died in his or her own home or in the home of relatives (e.g. children) or of people that they were close to (e.g. domestic partner).

n.s.: not specified.

Table 2, which gives an overview of places of death in cases of death from cancer, clearly demonstrates cross-national differences in the proportion of cancer patients. The share of cancer patients dying at home or at an institution is much more equally balanced in Germany (Papke and Koch 2007) and Majorca (Catalán-Fernandez et al. 1991) than in Sweden, where most cancer patients die in hospitals (Axelsson and Christensen 1996). Although most of the cancer patients died in hospitals in England, Germany, Switzerland, France, and the USA, the percentage of cancer patients dying at home is higher compared to the number of home deaths listed in synopsis 1.

Table 2: Distribution of places of death for cancer patients (data given in percent)

Author	Year	Location	Description of Sample	Sample(s) (n)	Hospital	Retirement (RH) and/or nursing home (NH)[1]	At home (AH) and/or other private residence (PR)[2]
Catalán-Fernandez et al.	1991	Majorca	Offspring of cancer patients and medical records	335	55	0	45
Axelsson, Christensen	1996	Sweden	Cancer patients	203	64	24 Ph	12
Higginson et al.	1998	England	Cancer patients	n.s.	1985: 58 1994: 47,3	n.s.	1985: 27 1992: 25,5 1994: 26,5
van Oorschot et al.	2004	Jena/ Thüringen (D)	Cancer patients	272/72	59	8	33
Gomes, Higginson	2006	13 countries	1966-2004, Meta-analysis of 58 studies of cancer patients	n.s.	n.s.	n.s.	UK, USA, Germany, Switzerland, France: 1994: 27 2003: 22
Papke, Koch	2007	Saxony (D)	Cancer patients	1997: 331 1998: 326 1999: 310 2000: 343 2001: 319 2002: 357 2003: 330	1997: 48 1998: 46 1999: 50 2000: 47 2001: 45 2002: 54 2003: 51	1997: 4 1998: 7 1999: 4 2000: 7 2001: 10 2002: 7 2003: 9	1997: 48 1998: 47 1999: 46 2000: 46 2001: 45 2002: 39 2003: 40

(Source: own illustration)

[1]: Not all of the studies reviewed make a distinction between retirement and nursing home.

[2]: Here, too, the studies fail to provide information whether the person died in his or her own home or in the home of relatives (e.g. children) or of people that they were close to (e.g. domestic partner).

n.s.: not specified.

In addition, the percentage of all cancer deaths occurring at home was 12.8 percent in Norway, 22.1 percent in England, 22.7 percent in Wales, 27.9 percent in Belgium, 35.8 percent in Italy and 45.4 percent in the Netherlands (Cohen et al. 2010). The proportion of cancer deaths taking place in hospital was 61 percent in Belgium, 31 percent in the Netherlands, 50 percent in England and 60 percent in Wales. In all populations except Norway, the proportion of home deaths was higher in patients with cancer than without (see Cohen et al. 2010: 2269). Retirement and nursing homes play only a minor role as yet in providing care for those suffering from cancer. According to Cohen et al. (2010: 2271) the

underlying reasons for this variation between countries can be traced back to the relationship between patients and physicians or general practitioners, government policies that are clearly directed at care at home, or the development of palliative care predominantly in hospitals. In sum, the differences result from a complex interaction of organisational, societal, and cultural factors (see Cohen et al. 2010: 2271).

Determinants of Places of Death

In addition, studies analyse medical, structural, socio-demographic, and individual factors determining each of these places of death. Those factors thus raise urgent questions for the debate on social inequality. The current state of research illustrates that places of death are not distributed at random but reflect social patterns, which will be summarised below.

The *type of illness or underlying cause of death* is one of the most important factors that determine the place of death. People who fall ill two to three months before death are more likely to die in hospitals compared to those who had been ill for more than two years prior to decease (Bowling 1983). The disorders most frequently leading to death in hospitals are cancer, stroke, and respiratory diseases (Bowling 1983; Fischer et al. 2004; Higginson et al. 1999). Among the different kinds of cancer, bladder and gastric carcinomas are the most frequent causes of death in hospitals (Catalán-Fernandez et al. 1991). Other studies mention breast cancer, haematological and lymphatic disorders (Cohen et al. 2006; Higginson et al. 1999), and neoplasia (Fischer et al. 2004) as the most frequent causes leading to death in hospitals. People dying at home are more likely to do so from cardio-vascular diseases (Fischer et al. 2004; Streckeisen 2001), Parkinson, ischemic heart disease, cerebrovascular, and special types of malign diseases (Cohen et al. 2006). The most frequent cancers leading to death at home are gastrointestinal and prostate cancer in case of men (Higginson et al. 1999) and breast cancer in case of women (Catalán-Fernandez et al. 1991; Papke and Koch 2007).

How might we explain the phenomenon that more cancer patients die at home compared to people not affected by cancer or people with any other illness as shown in synopsis 1 and 2 and observed by Bowling (1983), Fischer et al. (2004), and Higginson et al. (1999)? One explanation could be that suffering from this illness until death usually extends over months and years and typically involves high awareness, knowledge, and pressure to make decisions about further medical treatment by the mostly younger patients. As a result, the conditions required to plan for dying at home are given. Moreover, patients with the greatest likelihood of dying in a hospital are those whose disease takes an unexpected turn or who remain hospitalised while awaiting a vacancy in a nursing home. A patient may also remain hospitalised until death because of the wish to receive treatment to the end (Guthrie et al. 1996). There are different scenarios that could illuminate this wish. First, one reason to remain hospitalised can be traced back to the internalised rules associated with the role of being a patient and the expectation that medical technology still can save one's life. Second, the rules governing the interaction between patients and health professionals can be explained by the "cure" model and the "denial of death" in a modern health system. In brief, the hospital can best be characterised as an institution where the occurrence of death is perceived as a failure of medicine (Howarth 2007). Moreover, the wish to receive treatment to the end could also result from a lack of family members who are available and able to care for the dying person at home. Finally, the wish to remain in hospital can also be attributed to a lack of palliative care facilities in proximity to one's home (Bowling 1983).

The likelihood of dying in a hospital or retirement home increases with the *structural availability* of hospital beds and places in retirement homes. A low supply in the proximity of one's place of residence increases the likelihood of dying in a private home (Ochsmann et

al. 1997). For Swiss language regions, Streckeisen (2001) observes that dying in hospitals takes place much more often in French- and Italian-speaking Switzerland than in the German-speaking parts of the country. The greater incidence of dying outside the hospital setting in German-speaking Switzerland is traced back to the comparatively longer-established and more widespread provision of decentralised care facilities in this particular language region, which facilitates terminal care at home. In contrast to these findings, Ochsmann et al. (1997) did not observe any connection between the availability of out-patient care and an increased likelihood of dying at home. The socio-demographic factors investigated include *age*, *gender*, *family*, and *socio-economic status*. The hospital is the most frequent place of death for the age group under 45 while the proportion of hospital deaths among the age group over 60 declines steadily with increasing age (Bowling 1983; Fischer et al. 2004; Ochsmann et al. 1997). At the same time, the share of deaths in retirement homes rises among that age group (Ahmad and O´Mahony 2005; Bickel 1998; Fischer et al. 2004; Ochsmann et al. 1997). Younger people are more likely to die in a private home, be it in their own home or that of others, than those aged older than 90 years (Fischer et al. 2004; Streckeisen 2001).

Gender has also proven to be a factor of major influence. Men die at home more often than women (Cohen et al. 2006; Streckeisen 2001; Higginson et al. 1999). Family status also has an impact (Bowling 1983; Ochsmann et al. 1997; Streckeisen 2001): Singles without children, especially without daughters, die in the hospital more frequently than widows or divorcees, who are more likely to die in a retirement home. Men and married persons more often die at home (Bowling 1983; Ochsmann et al. 1997). This is considered the result of the higher life expectancy of women and the gendered division of roles and labour between men and women. Domestic care is the domain of women. This corresponds with the female role of the “caregiver” for the dying and is referred to as the “feminisation” of terminal care (Field and Small 1997).

A study on the place of death of cancer patients (Catalán-Fernandez et al. 1991) observed a larger proportion of patients with low socio-economic status dying in the hospital. A low income reduces the probability of dying at home (for a review, see Wilson et al. 2009). The impact of higher social class as a factor associated with congruence between preferred and actual place of death is supported by Bell et al. (2010). Educational level is positively related to the access of palliative care services (Bossuyt et al. 2011). Davison et al. (2001), on the other hand, found no connection between socio-economic status and the place of death.

Place of residence or, rather, *degree of urbanisation* is a factor whose influence on the place of death has been frequently confirmed. Thus, the likelihood of dying in a hospital is greater in urban regions compared to rural areas in Switzerland (Streckeisen 2001). In the countryside, more people die at home, only rarely in retirement homes, for example in Germany or Belgium (Cohen et al. 2006; Gomes and Higginson 2008; Ochsmann et al. 1997; Papke and Koch 2007). Moreover, physician support, hospice and palliative care home services as well as family support increase the likelihood of home death (Wilson et al. 2009; Bell et al. 2010; Houttekier et al. 2010). Having a preference for a place of death and having it communicated with caregivers is an individual factor in determining the place of death. It is a fact that patients who have an advance health care directive die in their place of choice significantly more frequently than those that do not (van Oorschot et al. 2004, 2005).

CONCLUSIONS

Although death and dying remain institutionalised, the sparse data on places of death fail to support the classic thesis of an increasing institutionalisation (Ariès 2005; Kellehear 2007;

Feldmann 1990, 1995; Nassehi and Weber 1989). According to Gronemeyer (2005), we are observing the institutionalisation of dying while dying in the family setting remains the "rhetorical ideal". Yet, the characterisation of hospital death as a "lonely death" (Ariès 2005: 730) is an inadequate description of reality and reflects a distorted image drawn by society. Bowling (1983), for instance, shows that in many cases dying people are taken to the hospital only in the final stage after a lengthy period of intensive care by relatives. Hence, the question as to what extent families today are less willing to care for the dying than in the past still remains to be answered (Ochsmann et al. 1997).

The term *institutionalisation* carries the negative connotation of being the typical form of dying in modern service societies. It evokes images of loneliness, isolation and helplessness (e.g. Stephenson 1985; Elias 2002; Gronemeyer 2005, 2007; Göckenjan 2008; Greil 2008). In this largely unexplored area, however, a normative evaluation of places of death as "good" or "bad" is not possible as long as we lack properly defined criteria and empirical findings.

Does institutionalisation amount to a greater publicity of death in society due to the situation of dying leaving the privacy of the individual home, or must we interpret it as a process of suppressing the topic of death and dying (Nassehi and Weber 1989)? Dying in hospitals or nursing homes can thus also be read as the antithesis to suppressing death or rendering it taboo (Nassehi and Weber 1989). Dealing with dying persons becomes visible to a greater number of people when taking place in a public institution. At the same time, hospices and palliative care units establish new forms of institutionalisation and also seek to raise society's awareness of death and dying.

The fairly high and, over many years, constant percentage of people dying at home ranging between 20 to 30 percent additionally casts doubt on the classic institutionalisation of dying thesis. Thus, dying in institutions cannot simply be deemed the "normal case" (Feldmann 2004) in modern society. Moreover, there are signs for a shift from hospitals to retirement homes (Ochsmann et al. 1997). In this context, the consequences of demographic change and the increasing proportion of elderly and single women must be mentioned. Retirement and nursing homes will play an increasing role as places of death and their number can be expected to grow accordingly. Family members will experience greater difficulties in providing care for their loved ones in the future due to increasing participation in the workforce (Fischer et al. 2004; Göckenjan 2008). This fact may also involve a shift in the experience of dying and possibly in the quality of dying since for many people residing in retirement or nursing homes, their retirement or nursing home actually becomes their "home". The culturally pessimistic contention that modern society engages in a "practice of excluding the dying from the community of the living" (Feldmann 1990 – translated from German), which is traced back, among other factors, to the increased employment and social emancipation of women, calls for critical questioning. There is also little evidence for an "erosion of the family" (Gronemeyer 2007) which takes its dying family members to the hospital for lack of time or ability to care for them.

Our review shows that places of death are not distributed at random but reflect social patterns. Dying persons heavily rely on their social environment, its capacity to act and the available resources and institutions. Dying at home is not an opportunity that is equally available to everyone - we first have to create structural conditions that allow people to die in the place of their choice. Socio-demographic relationships involve factors such as gender, socio-economic status, family status, or the degree of urbanisation (e.g. Cohen et al. 2006; Dreßel et al. 2001; Ochsmann et al. 1997; van Oorschot et al. 2004). Those factors point to social inequalities and thus raise urgent questions for the debate on the place of death. For

dying to take place at home, certain conditions must be given: a) individual factors (e.g. a sense of obligation or emotional ties for the motivation of relatives), b) socio-economic factors, and c) institutional and structural conditions (e.g. ambulatory palliative care services). Basic requirements for dying at home are relatives that are able to cope with the situation both physically and emotionally, the availability of ambulatory palliative care, and suitable conditions in terms of space and availability of the necessary technical equipment for care (Wittkowski and Schröder 2008). Receiving physician support, hospice and palliative home care visits have increased the likelihood of home death (for a review, see Bell et al. 2010). Nevertheless, contemporary society is marked by the insufficient availability of hospice or palliative care facilities for the dying in many parts of Europe, both of the in-patient and especially of the ambulatory kind. This affects the rural population more strongly than the residents of urban agglomerations (Bell et al. 2010).

An advance health care directive is an important instrument to record a preference for place of death and communicate with caregivers and physicians (van Oorschot et al. 2004, 2005). In addition, the time frame of events must leave room for weighing opportunities and restrictions in favour or against the respective place of death and allow a deliberate decision to be made. In many cases, fatal illness leaves no choice, and the hospital remains the only option if only for medical reasons. Assurance that proper treatment for symptoms is available, a sense of security, or the desire to relieve relatives of the care burden, are factors that may contribute to explaining the preference for in-patient care (Glaser and Strauss 2007). The studies also point to the emotional burden on relatives as caregivers of the dying (Cohen et al. 2006; van Oorschot et al. 2004) and the psychosocial consequences – an aspect that must not be neglected in the discussion about places of death.

However, the available studies primarily pursue medical or demographic research objectives. The result is that while we do know who dies, where they die, what the medical causes are, what socio-demographic factors are involved, we do not know how the dying or those that act on their behalf arrive at their understanding of the situation or at the decisions to be made or actions to be taken as the process of dying takes its course. The existing studies leave in the dark how perceptions and actions concerning the place of death are affected by the knowledge, wishes, experiences, and emotions of individual actors, by the communication between them, in their social networks, as well as in the setting of the respective institutions. These aspects thus constitute a core desideratum in current end-of-life research.

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